

# Centers for independent living and transition-age youth: Empowerment and self-determination

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**Abstract.** A primary function of centers for independent living is to empower individuals with disabilities and to support greater independence. These functions overlap with the purpose of transition planning for youth with disabilities, and it is increasingly evident that CILs can play an important role in such transition services. This article discusses the potential role of CILs in transition services for youth with disabilities, particularly in promoting self-determination, and provides an example of a program that CILs could replicate to achieve such outcomes.

**Keywords:** Centers for independent living, transition services, adolescents, self-determination, empowerment

## 1. Introduction

Centers for independent living (CILs) have long been in the business of providing community-based support services to people with disabilities [13]. However, the provision of transition services to youth and young adults has, mostly, been the responsibility of school systems. Lattin and Wehmeyer [5] documented that CILs can and, increasingly, do serve an important role in supporting youth with disabilities to transition from secondary education to adulthood. In a national survey, Lattin and Wehmeyer found that CILs provided an array of transition-related supports, including job training and coaching, benefits advocacy, transportation training, and training to empower youth and promote self-determination. It is this latter role that is the focus of this article.

Despite the potentially important role CILs might play in supporting the transition of youth with disabilities,

Lattin and Wehmeyer found that fewer than half of CILs had any focus on this population and most had only minimal contact with youth. This is likely a function of the fact that transition services are the responsibility of public schools. It is also the case that CILs and public schools have, historically, operated under differing philosophies. The independent living movement emerged from a strong empowerment and self-determination emphasis, while education has historically been aligned with medical models and/or a deficits-reduction focus.

However, the seeds for more meaningful collaboration between CILs and school districts were sown in 1990 when Congress reauthorized the Individuals with Disabilities Education Act (IDEA), the federal legislation that mandates a free appropriate public education for all children with disabilities. IDEA required, for the first time, that needed transition services be addressed in every student's Individualized Educational Program (IEP) when they reached the age of 16. The intent of the transition mandate was to ensure that all students received educational programming that adequately prepared them for adulthood.

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Significantly, the Act also required that the coordinated activities: (1) be based on individual student needs, and (2) take into account student's preferences and interests. These requirements, generally referred to as the 'student involvement' requirements in the transition mandate, were consistent with the intent and spirit in other disability legislations like the ADA, which emphasized empowerment, participatory planning, and greater control for recipients of such services [10]. These amendments moved the IDEA focus closer to that of the empowerment and consumer-control focus inherent in the independent living movement. This emphasis was further strengthened by the U.S. Department of Education, which funded multiple demonstration, research, and outreach projects through discretionary funds to promote self-determination for youth with disabilities and to encourage student involvement in educational planning and decision-making [7,9]. Self-determination has become a key area to address in transition programs for youth with disabilities [2].

Perhaps because of the alignment between schools and CILs on issues like the importance of community integration and consumer direction and control, Wilson noted:

In the last few years, CILs have played an increasing role in the provision of transition services through the development and implementation of CIL-specific programs and services and as part of collaborative, multidisciplinary, community-based transition teams. Because of their unique administrative and operational organization, CILs have begun to play an integral role in the support of youth and young adults in transition. As a result, local, state, and federal agencies are continuing to determine the short and long-term role of CILs in support of transition (1998, p. 247).

As evidence of this emerging collaboration, Wilson gives examples of CILs who have exemplary programs in supporting transition-age youth. One CIL, in metropolitan Detroit, provided leadership, job-readiness training, and paid volunteer and job experience for transition-age students. A second program offered by a CIL in central Virginia, built a statewide network of mentors and peer counselors with whom to link transition-age youth. These examples and information from Lattin and Wehmeyer [5] illustrate that the historic divide between CILs and secondary education may be narrowing. Moreover, with the focus in transition on student involvement and self-determination, there is even more need to identify how CILs might become key players in empowering young people to be-

come more self-determined and to take greater control over decisions and actions leading to outcomes like employment and independent living. This article provides a brief overview of self-determination and transition age youth and provides a description of the involvement of a CIL in an "empowerment" group organized for adolescents with disabilities designed to promote self-determination and student involvement.

## **2. Self-determination**

There is insufficient space available in the context of this article to provide more than a cursory overview of self-determination and transition-related services. Interested readers are referred to Wehmeyer et al. [8], Field et al. [2] and Wehmeyer et al. [9] for more comprehensive explorations of this topic. Put most simply, the self-determination construct refers to both the right and capacity of people to exert control over and direct their lives. In reference to a right, the construct's use is grounded in its meaning referring to the political right of people or peoples to self-govern. Disability advocates and activists have stressed the inherent right of people with disabilities to assume responsibility for and control over their lives [4,6]. In the 1990s, promoting and enhancing the self-determination of students with disabilities, particularly as a function of the transition planning process, became best practice [9]. These efforts focused on enhancing student capacity to become self-determined and exert control in one's life by promoting goal setting, problem solving, decision making and self-advocacy skills and focusing on efforts to promote opportunities for students to use these skills.

A variety of definitions of the construct have emerged from efforts in special education. Field et al. [2] summarized these various definitions of self-determination by stating that self-determined people apply "a combination of skills, knowledge and beliefs" (p. 2) that enables them "to engage in goal-directed, self-regulated, autonomous behavior. An understanding of one's strengths and limitations together with a belief in oneself as capable and effective are essential in self-determination. When acting on the basis of these skills and attitudes, individuals have greater ability to take control of their lives and assume the role of successful adults in our society" (p. 2). Field et al. [2] further delineated the common components of self-determined behavior identified across multiple self-determination models or frameworks. These include (a) awareness of personal preferences, interests, strengths, and lim-

itations; (b) ability to (i) differentiate between wants and needs, (ii) make choices based on preferences, interests, wants and needs, (iii) consider multiple options and anticipate consequences for decisions, (iv) initiate and take action when needed, (v) evaluate decisions based on the outcomes of previous decision and revise future decisions accordingly, (vi) set and work toward goals, (vii) regulate behavior, (viii) use communication skills such as negotiation, compromise, and persuasion to reach goals, (ix) assume responsibility for actions and decisions; (c) skills for problem-solving; (d) a striving for independence while recognizing interdependence with others; (e) self-advocacy and self-evaluation skills; (f) independent performance and adjustment skills; (g) persistence; (h) self-confidence; (i) pride; and (j) creativity.

Even this brief overview of the construct should illustrate the potential impact that centers for independent living can play in promoting the self-determination of youth. While typically positioned as a movement toward independent living, one could quite easily argue that the real mission of CILs is to promote the self-determination of people with disabilities.

### **3. Is self-determination important for students with disabilities?**

In a word, 'yes.' First, promoting choice and self-determination is mandated by federal disability policy and legislation from the transition-mandates in IDEA to the choice requirements in the Rehabilitation Act. Second, there is growing evidence from the special education literature that enhanced self-determination leads to more positive adult outcomes, outcomes equally valued by the field of rehabilitation. Wehmeyer and Schwartz [12] measured the self-determination of 80 students with mild mental retardation or learning disabilities in their final year of high school. One year later, students who were more self-determined were more independent and were more likely to be employed for pay. Eighty percent of students in the high self-determination group worked for pay one year after graduation, while only 43% of students in the low self-determination group did likewise. Among school-leavers who were employed, youth who were in the high self-determination group earned significantly more per hour ( $M = \$4.26$ ) than their peers in the low self-determination group ( $M = \$1.93$ ).

Wehmeyer and Palmer [11] conducted a second follow-up study, examining the adult status of 94

young people with cognitive disabilities (mental retardation or learning disability) one and three years post-graduation. These data replicated results from Wehmeyer and Schwartz [12]. One-year after high school, self-determined students were disproportionately likely to have moved from where they were living during high school and, by the third-year, were still disproportionately likely to live somewhere other than their high school home and significantly more likely to live independently. Self-determined students were disproportionately likely to hold a job by the first-year follow-up, working either full or part-time and to have held a job or received job training by year 3. For those students across the sample who were employed, students scoring higher in self-determination made statistically significant advances in obtaining job benefits, including vacation and sick leave and health insurance, an outcome not shared by peers in the low self-determination group. Overall, there was not a single question on which the low self-determination group fared better than the high self-determination group.

Third, there is a growing body of evidence in the field of vocational rehabilitation that, in particular, enhancing choice opportunities leads to better VR-related outcomes. For example, Farley et al. [1] evaluated the impact of strategies to enhance consumer choice and involvement in the VR process and found that consumers who were actively involved in VR planning enhanced vocational career development outcomes. Similarly, Hartnett et al. [3] compared costs, services received and outcomes achieved for people served through the typical VR system and people involved in a "Consumer Choice Demonstration Project" in Vermont. They found that the Choice group was two times more likely to have completed rehabilitation and their mean income was 2.7 times higher.

In summary, promoting self-determination is both best practice in transition services and has been empirically validated as contributing to more positive outcomes. Because of the historical role of CILs in promoting greater independence and self-sufficiency, it would seem a logical extension of existing practices for CILs to play an active role in promoting the self-determination of transition-age students with disabilities. The remainder of this article describes one program that could easily (and inexpensively) be replicated by CILs to achieve this outcome.

#### 4. An empowerment group for adolescents with intellectual and developmental disabilities

RRTC-ILM investigators at the University of Kansas approached staff at Independence, Inc., a center for independent living in Lawrence, Kansas to participate. The initial phases of the process involved meetings between project staff and Independence, Inc. staff, including the educational advocate and the peer-counseling specialist, to come to agreement on the goals of the activity and on the content and process. After the first few meetings, personnel from the Lawrence public school district who worked with adolescents with disabilities, including the district transition coordinator and the teacher at the high school located nearest the CIL, were invited and became partners in the planning process. While project staff at KU supported the design phase, the primary decision makers in the process were the staff at Independence, Inc. and educators from the Lawrence schools.

As the discussions progressed, it was agreed that an “empowerment group” would be beneficial for youth with disabilities and would fit the mission and the capacity of Independence, Inc. There were a number of characteristics that the planning group wanted the empowerment group to possess. One of the most important was to distinguish this group from a school activity. The goal was to design a comfortable setting where students would feel free to express their own ideas about what they wanted their future to look like. Equally important, the planning team wanted the students to take ownership of the group. Though there was an agenda of material that they agreed should be covered, there were also aspects of the group activities that the participants could assume control over planning. These included choosing the name of the group, the rules for the sessions, and what kind of food and drink they wanted at each meeting.

Project staff assumed responsibility for developing the curriculum to be covered during the empowerment group sessions. The intent was to draw on existing resources and programs that would be readily available to other CILs. The first source was the promising practices identified from CIL’s that responded to the Lattin and Wehmeyer [5] survey. These included training materials on advocacy issues, independent living issues, and on consumer rights and responsibilities. Other activities were derived from curricular and instructional materials to promote self-determination that are used by and widely available to schools were incorporated. The planning team determined that the most effective

solution to transporting students to the CIL was to request a district school bus be made available. Finally, the peer-counseling coordinator at Independence, Inc. recruited several peer counselors to participate in the group sessions.

*The Curriculum.* The objective of the curriculum was to familiarize the student members of the empowerment group with some of the core concepts of self-determination and to introduce the notion that they could participate in their own transition planning activities, such as being actively involved in their Individualized Education Program (IEP) meeting.

Due largely to the school calendar, the group was scheduled to meet once per week for eight weeks, with each session lasting for an hour. The first session was introductory in nature. Students and participating staff (from Independence, Inc. and the high school) were introduced to one another. This was done by everyone participating in icebreakers. Then, two group facilitators, both adults with a disability, one affiliated with the university and the other the peer-counseling specialist, reviewed the purpose of the group and meetings. In the second session, students were provided time to make decisions about a number of aspects of the group. At this time they picked a name for the group (*Friends for Life*), established rules for the group, and decided what type of food and drink they wanted at these meetings.

The first activity students engaged in was to describe themselves and their goals for the future (if they had any) to the rest of the group. This was completed in small groups. Members of each group decided how they wanted to present the information from their group. They were encouraged to use any format they wanted, from making a collage or writing a poem to presenting the information in a skit. This gave the group members an opportunity to think about themselves and what they wanted their futures to look like. For some of the students this was the first time they had been asked to think about these issues. Thus it took time for them to design their presentation. Nevertheless, at the end of the session, each group stood in front of their peers and presented what they accomplished. This was also a new skill for some of the students.

The following two sessions were dedicated to goal-setting activities. Students were asked to formulate a goal (educational, independent living, or recreational) based on the future they had described in the previous session and which could be included in their next Individualized Education Program (IEP). This was not an easy task for several of the students. Group facilitators and other adults with disabilities from the CIL’s peer

Table 1

DO IT! problem solving strategy from Whose Future is it Anyway?

Initial	Activity
D	Define the problem.
O	Outline your options.
I	Identify the outcome of each option.
T	Take action.
!	Get excited!

counseling staff worked individually with them to support them in developing their goals. Students were supported to define their educational learning need, outline options that addressed that need, identify outcomes of each option and finally, take action. To achieve this, students were taught a decision-making process called DO IT! (see Table 1) that students applied toward making decisions about their transition outcome areas. Using this process, students were able to devise a plan that would assist them to obtain their goal.

Aside from teaching students the skills they needed to take a leadership role in their transition planning, it was deemed as important to provide them with information about the CIL and what type of services were offered that might be helpful to them once they graduated. For this segment, staff from the CIL came to the group and talked about the various services that Independence, Inc. could offer them, such as assistance with independent living, advocacy and public transportation. This was informative to the students. A number of the students signed up for different activities that the CIL offers outside of the *Friends For Life* group.

For the final activity, students were asked to choose something they wanted to do to celebrate the end of the group meetings. They were informed that they could do anything they wanted, however, they had to plan everything from what they wanted to do to what type of transportation they were going to use to get there and back. The students began by listing various options available to them while a facilitator wrote their ideas on a flipchart. They then voted. The proposal that won was to go bowling. Students then listed all of the actions they would need to take and potential barriers to achieving those actions on a flip chart. Next, students listed possible solutions to each of the problems and chose the best one. At the end of the session they developed a plan that enabled them to enjoy an evening of bowling and pizza. In addition to the event itself, students also expressed satisfaction about the fact that they planned the event by using the skills they had learned during the group meeting.

## 5. Conclusion

This relatively simple and inexpensive activity improved the CIL's connection to transition-aged students in their community. By offering this type of group, the CIL demonstrated that they could make a vital contribution to assuring that students with disabilities have a successful transition from school to adult life. We suggest that by considering activities such as this empowerment group activity CILs can play a meaningful role in the lives of transition-age youth and further the CILs impact in their community.

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